

# IMMUNIZATION REGISTRY FOCUS GROUP STUDY

September 23, 1998

American Indian, Higher Education

Tulsa, Oklahoma

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## SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

### I. Prevention

Diseases mentioned:

- Leukemia/Cancer
- Diabetes
- Muscular Dystrophy
- Measles
- Mumps
- Rubella
- Tetanus
- Hepatitis
- Chickenpox
- Polio
- Tuberculosis

### II. Immunization

#### A. *Reasons not to get vaccinated*

- Lack of money
- Ignorance
- Possible health risk to child
- Religious reasons
- If child receives vaccine, someone in the family may become sick

#### B. *Reasons to get vaccinated*

- Doctor's recommendation
- Fear of childhood diseases
- To enroll in school
- To protect children
- It's the rule

#### C. *Ways parents are reminded of vaccine schedule*

- Shot record
- When doctor says it's time

- Books and magazines have the schedule
- Indian Hospital staff
- Television
- Schools/Sports physicals
- Day Care

#### ***D. Methods of easier tracking***

General consensus that the “cards” worked well to track immunizations.

## **SECTION 2: IMMUNIZATION REGISTRIES**

### **I. Initial reactions to the idea of a registry**

- Respondents’ initial reactions were positive but skeptical. They noted positive aspects such as ease of transferring records and not need to carry card to the doctor’s office. However, respondents also and raised questions of cost, access, and whether certain populations would be tracked.

*What’s it cost?*

*It’s like Big Brother.*

*I can see where [tracking immunizations] would be difficult, and [the registry] would be better if you switched around to different doctors or weren’t able to see the same doctor every time.*

*I know we’re talking about children here, but I have to say that there are shots we have to keep up with, like tetanus. I know I have no clue as to when I had my last whatever shots. It would be nice for adults I think.*

*I remember there was a man that was in downtown Tulsa who used to go every weekend, every weekend he’d stand up in his little box and talk about how the government was immunizing but they weren’t really immunizing, they were sterilizing. Has anyone ever heard of that? If they can segregate you by a registry and then who’s to say they can’t give you a certain batch of medicine or immunizations.*

### **II. Content of the registries**

#### ***A. Initial reactions to the type of information typically in a registry***

- Respondents quickly noticed that the father’s and the doctor’s name was not included. The skepticism continued.

*Too much control.*

*Like giving your credit card out on the Internet.*

*It's great, but I question the motive.*

*We were talking about earlier how you had to follow the rules and that's probably why you get them immunized. Every bit of this information, you give a copy of that card too, the school system, they have every bit of this here.*

**B. Reactions to including home address and phone number**

- Respondents preferred using the doctor's information versus child's home address and phone number for tracking.

*I want somebody that knows me to contact me. Because I don't know if I would trust somebody that called me up that I had no clue [about who the person is].*

**C. Reactions to Social Security Number**

- Most respondents were comfortable with using the SSN stating they gave it out frequently without any problems.

**D. Reactions to including healthcare members enrollment (WIC, Medicaid numbers, tribal enrollment numbers)**

- There was concern that having WIC or Medicaid information might single someone out as being low income. There was also concern that tribal enrollment numbers could be used to single out American Indians.

*You don't necessarily want people to know you are involved in WIC.*

*It's not everybody's business.*

**III. Access**

**A. Who should have access**

- Hospitals/emergency rooms
- Doctors
- Company that made the vaccine

**B. Who shouldn't have access**

- Health insurers
- American Online
- Unauthorized persons
- Schools
- When probed about whether or not researchers should have access most felt this was not necessary.

**C. Reactions to the idea of linking registry by computer to other health information systems**

- The respondents were in general agreement that such links would be unnecessary.

**IV. Consent and Inclusion**

**A. Reactions to “opting out” option**

- The responses were neutral to negative. Some noted that this is the easiest way for those who sponsor the registry to build the registry.

*What if the mail never makes it to your house---without your consent and they just assume that you wanted it.*

*There is no advantage or disadvantage that I can see.*

**B. Reactions to “consent” option**

- The general consensus was that having the choice was positive and that by giving consent parents might be more aware of immunization issues.
- A few noted that with this option not as many children would be enrolled in the registry, therefore many children would not be contacted if vaccine batches were bad. Also, vaccine information in general would be incomplete.

**C. Reactions to “automatic” option**

- A few were adverse to the idea, but many were willing to accept the option or noted its advantage over the other options.

*I’d move.*

*It’s a Big Brother issue.*

*If that were the law I’d accept it, I wouldn’t fight. I wouldn’t have any other choice if that were the law.*

*Well there would be no segregation of certain groups of people, it would just be every kid goes in no matter what.*

*I can see the advantage because of the thoroughness of the data base, and if there was a bad batch we would know how many kids had that bad batch.*

**SECTION 3: WRAP UP AND CLOSING**

**I. Most important benefits of registries**

- Notification of bad batch
- In case of loss of card
- Information readily available
- Increased awareness about immunization overall
- Convenience
- When probed about preventing multiple shots or providing warnings about medical conditions, most participants did not recognize these as important advantages.

*One benefit for me because I carry all the immunization cards with me and my husband doesn't have a clue as to what my kids have, if you had something like this and I wasn't available, my husband wouldn't be going, oh I don't know, I don't know. Here it is right here.*

## **II. Greatest concerns/biggest risks**

- Incorrect information
- Segregation issues
- Might put pressure on those who choose not to immunize
- Where the information might be going
- When probed if they were concerned about being denied health benefits, several voiced their concern.
- When probed about being denied entry into school, several noted that current school policy already denies entry to those with out immunizations.

## **III. Influence of healthcare provider in decision to participate in a registry**

- Respondents said they would not be influenced by a doctor's opinion of the registry. A few noted a lack of relationship with Indian Health Service doctors as the reason for this lack of influence.

*Not at the Indian Hospital.*

*You don't see the same doctor every time so you don't have a relationship.*

## **IV. Suggestions/comments to people who are responsible for how system works**

*I would be for the registry only if I could give my permission and know exactly what was on it and who exactly wanted to know the information before I give them permission to have the information.*

*The only way I see this would be beneficial if it were all or none.*

*I would just tell them that I was able to keep track of my own kid's shot records. I didn't need their registry. I thought it was a waste of time and waste of money. Spend money on something else.*